Concurrent Session Two – Translation Issues/Taxonomy Populations

Kira Sloop
Kata Chillag
Tippavan Nagachinta
Reverend Tommie Watkins
Marquietta Alston

As in the earlier session, which was the identical topic to this, Kira Sloop called the session to order. She explained the purpose and the format of the session, and then introduced the panel members who delivered overview presentations, and/or engaged in deliberations with the participants. Kata Chillag, CDC Representative, reviewed the categories of populations that interventions are designed to address. Tippavan Nagachinta then briefly spoke to the group about the technical assistance (TA) that is available to them. She reviewed the same information she did in the earlier session. As he did in the morning session, the Reverend Tommie Watkins addressed the group about his faith-based HIV prevention education program in Miami, Florida. Marquietta Alston addressed the group regarding the Virginia Health Department.

Discussion Summary:

Following the Presentations of Kira Sloop, Kata Chillag, and Tippavan Nagachinta

- A participant asked about the length of time between submitting a request and actually receiving the TA.

- Tippanvan Nagachinta replied that the time frame varies according to the request, and that more details would be covered in the morning session. She said that they hoped to be able to provide health departments with an idea of the turnaround time to help them in their planning. Nikki Economou added that in some cases, the response can come as fast as in 48 hours.

Following Reverend Watkins' Presentation

- A participant inquired as to how the two books Reverend Watkins described are used.

- Reverend Watkins replied that the first hour of the service is a book study, while the second hour is a traditional church service. The books are special because often in the Black church, people with HIV or with different sexual orientations are stigmatized or marginalized. They give the books as gifts to local faith-based leaders for them to use.

They help the clergy address these people and help the church to be more inclusive, he said. He feels that the old approach from the church is one of the reasons that HIV has such a high incidence in the black community.

Following Marquietta Alston's Presentation

- An inquiry was posed as to why MSMs were included in both "population" and "risk" categories.

- Marquietta Alston replied that when CPG did their prioritization, MSM was identified as a target population in and of itself, and it happened that CDC includes that category as a risk behavior. The form, then, has space for both. If MSM is marked as a population and not a risk behavior, then the state will ask the contractor why.

- Another audience member noted that his state collects information the same way as Virginia, and he encounters problems when asked to sort out, for instance, how many Black, MSM, IDUs are reached by a given intervention.

- Marquietta Alston said that Virginia has not sorted out that problem either, but that there is a way that contractors can indicate that they are working with, for instance, PWAs, so they can partially answer the question.

- A CDC representative asked about trans-genders, which are not included as a population group. He also inquired whether the definition of "youth" was according to CDC guidelines, or if the state used another definition.

- Marquietta Alston responded that the trans-gender issue had come up, and so the state encourages their contractors to focus on what risk behavior they are trying to reach. Also, there is not much work being done in the trans-gender population. The CPG is talking about the issue, she said, so some changes are possible. She said that they use the CDC's definition for "youth." One of their problems is working with inconsistencies in age ranges and definitions.

- A participant asked how long it takes to complete the forms.

- Marquietta Alston replied that she did not know how long it takes to fill out the intervention sheets, although she said she has heard no complaints that it takes too long to complete them, probably because the contractors have been involved in the process all along.

- It was noted that standardization is difficult when age ranges are different. For instance,

"youth" is defined as under 24, but the age ranges are "below 19," and "20 - 24." In academic settings, "outcome" and "impact" evaluations are the exact opposite of what CDC uses. There have been conflicts between the language that CBOs use, then, and the language that some evaluators use.

❖ Kira Sloop acknowledged that that had been a debate for decades. No changes are expected becase people in the evaluation field cannot even agree on the issue.

Kira Sloop then divided the session into smaller discussion groups. She reminded them that David Napp had identified three strategies for translating local populations into CDC's data collection system:

❑ A combination of CDC terms and local terms;
❑ Contractors' complete adoption of CDC taxonomies; and
❑ Contractors use their own, local terms, and the health department translates the data to send to CDC.

As with the earlier session, she asked the small groups to reflect on their systems, their challenges and how they have overcome them, whether there are target populations that are not being addressed by the CDC categories and how they have coped with that, and how CDC can help them with the translations. This group did not report out as did the first group. Instead, they engaged in an open discussion period.

Discussion Summary:

❖ A participant inquired as to how Virginia went about allowing their contractors to use their own categories. He described how his CPG had divided his state's population into target populations and then designated interventions for each of them. Each client would have fit into several of those categories which made it very confusing. When interventions are targeted to a neighborhood, they had to guess what populations lived there. He also wondered how many contractors would say that they had an insufficient delivery plan for one of their activities

❖ Marquietta Alston replied that at the state level, they did not do service delivery for contractors. Their work plans were created in-house, and then state staff would evaluate them so that their categories were acceptable. They encourage their contractors to incorporate behavior theories into their plans, and they also had in-person training sessions.

❖ A participant from Georgia described her state's training, which combines in-person sessions with follow-up session. Most of their agencies have fairly straightforward target

populations, she said, but some agencies have had trouble with the new terms – in particular, an agency that has group-level, individual, and outreach services to migrant farm workers. These people are not allowed out of their camps, so the interventions are hit-and-miss. The contractor found that group interventions with the commercial sex workers who work with the migrant farm workers were a good way to access that population. Another agency that used media such as billboards had trouble linking their efforts to the new terms as well, but the state was able to work with them to refine their campaigns. They have quarterly meetings.

- A participant from Oregon, where they initiated a new priority-setting process, said that they decided to adopt the CDC taxonomy and then use sub-populations to better define the populations. For example, MSM was their top population in both urban and rural areas. The first sub-population was MSM of color, followed by young MSM. They tried to capture all of the populations that they had accessed in the past and apply them to the CDC categories. He believed that there should be an HIV-positive category, as interventions are very different for that population. With the CDC's push toward serving persons with HIV, it made sense to add that category.

- Linda Kay of the Behavioral Intervention Research Branch works on the Prevention Research Synthesis Project, and they are collecting information on all HIV interventions since 1988, trying to synthesize and categorize the interventions. They have run into the same problem trying to get enough information about interventions. She asked if there was any thought going toward including six behavior categories to capture risk, but to add other, important population characteristics. For instance, the "heterosexual" category is not enough for youth, which gets such different interventions.

- Nikki Economou commented that those points were consistent with other comments. They have to look at the behavioral and then look at contributing factors, which would include HIV status, homelessness, incarceration, prostitution, and drug use that is not injection drug use. All of these factors contribute to behavior. To capture that information, she said they would all have to use their own categories. To work from a national perspective, though, there has to be consistency.

- Another participant commented that the issue of trans-genders has been one with which they have struggled. Their CPG has trans-gender representation, and those representatives do not want to be categorized as MSMs. They are thinking of sub-categories, because there are categories even within trans-genders. The relationship between the African-American community and MSMs is very strained. They are adding HIV status as a category overall and reinforcing with their facilitators to gather that information along with basic demographics, anonymously. This information will also help guide future services.

- In speaking with a group of trans-genders, another participant said they discovered great variety within that group. Some of them went from being men to being women who are having sex with women. The issue has come up in New Mexico, commented another attendee. She asked her trans-gender co-chair of her CPG about his feelings, and he related to her that the risk issues were not only about *with whom* people were having sex, but also having to do with the "affinity grouping" and the increased isolation that he felt within the MSM social network. There is a sense of shame within the more "macho" MSM community which points out that risk behavior is defined by a number of issues.

- Another speaker told the group that his CPG advocated making MSM and gay men two separate categories. The idea behind the split is that there are many MSMs who do not identify as gay men, and there are gay men who have a culture and a community. They are two very different things. MSM was left as the primary category, but they did keep gay men as a separate group to target because of the differences in how the two groups should be targeted.

- Kata Chillag commented on the CDC perspective, reminding the group that CDC sought a basic set of risk-behavior-based categories. This is not the whole compendium of CDC's interests, she assured them. They know that there are limitations to the categories, and they struggle with them, too, but they really want a common language for the country. She said they also wanted to hear about other activities in the narrative portions of the data collection forms.

- Nikki Economou pointed out that, for instance, a gay man who is Latino may identify himself first as a gay man, then as a Latino, or vice-versa. The intervention will depend on how an individual perceives him- or herself. The interventions are related to the populations.

- Another participant said he appreciated CDC's dilemma given that at the state level, he feels mistrust from people at the local level. It does translate when they miss populations, though, and people feel that CDC is not collecting information on a given population. If the data is not collected, then people are not going to own the responsibility for the epidemic. He realized that it was difficult, but stressed that the message has to get from CDC to the community that their HIV concerns are being addressed.

- Kata Chillag said she understood local situations, and added that any national instrument will miss data points, which may have real consequences for the interventions that are being designed and how agencies deal with their communities.

- Ms. Kay mentioned her project's difficulty in linking the mode of transmission to the intervention. She realized that they had already made changes to the Guidance, and knowing that, she expressed her hope that CDC would consider keeping the mode of transmission, but adding another component for the populations. There could be consistency with this method.

- Kelly Bartholow indicated that this process has gone on in consultation with local health departments. The Guidance is intended to consolidate the categories, not to eliminate variables that are useful at the local level. CDC needs the categories for its minimum core data set, but that does not mean that a helpful local process should be ignored or replaced completely. In the next funding cycle, she said comments like these would probably be incorporated. The Guidance will be revised. She reminded them that they are trying to capture contextual issues in the narrative, so health departments and CBOs can provide the bigger picture of their work to augment the data points.

- Nikki Economou asked what CDC could do to help them make these translations.

- A participant from New Mexico commented that the issues of how risk groups are described, defined, and prioritized are not just about the epidemic, but also are about deciding where money goes. For that reason, the taxonomy becomes even more important, especially at the CPG level. Because of this impression that the funding channels are related to the taxonomy, the trans-gender issue is a contentious one at the community level, she said.

- Kelly Bartholow recognized that point, because health departments have to report how their funds are tied to the surveillance data. There is a mechanism to address that gap, if it exists, but it is a legitimate concern.

- Nikki Economou pointed out that community planning is included in the process to help them direct monies more efficiently and effectively, according to the needs of the individual area. The epidemiology alone is not enough, she said.

- A participant said that he could live with translating up to the CDC categories if there were an official way to capture the other information. He expressed hope that people would be able to get at the data so that they know that populations are not being missed.

- A participant from Idaho expressed concern about the evaluation tools not from the contractor level, but the feedback from the field was in the area of people who are expected to identify those who attend interventions who may not show up on epidemiological data. In a rural area, with a limited number of people and limited number of meeting places for the gay community, the facilitator can identify respondents

quickly, even if the information is confidential. More broad categories are better for her situation, as self-identifying into even smaller categories will make things even more difficult for the people who conduct interventions and outreach. Anonymity is impossible in a community like that one, she said.

- ❖ Another participant told the group that he stresses with his contractors to think of the intervention first. They should be able to collect the data that they can reasonably collect without interfering with their intervention goals. A multiple-session workshop will yield a more detailed picture than an outreach activity, he said. Broad categories may be easier, but they do not give a full picture of the work that is being done. Perhaps there is a way to highlight special programs and disperse information about more specific populations.

- ❖ The representative from Georgia said that her epidemiologist meets with the CPG. Based on those requests, he highlights special populations within the epi profile. This way, the data is captured. They only recently made Asian/Pacific Islander a separate category.

- ❖ A participant suggested that the way that CDC could help the departments of health is to give their data back to them in a useful format. Some health departments will conduct outcome evaluation to show the effectiveness of their interventions. More detail would make those reports more useful. The different branches are working together more efficiently at CDC, so they are able to make each others' jobs better.

- ❖ Marquietta Alston inquired about outcome evaluation and what they could do. They are not supposed to do quasi-experimental projects.

- ❖ Kelly Bartholow replied that they are in negotiations with IRBs about what projects are appropriate. They should not use prevention money to conduct research.

At this point, a number of members in the group requested that the remainder of the IRB discussion be allowed to take place off the record. Therefore, the rapporteur turned off the recording equipment and ceased making notes via laptop computer.